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IF I TELL YOU, WILL YOU TREAT ME?

MAURO A. MONTOYA, JR.*

"I have bad news for you. Your HIV test came back positive." I heard those words on Columbus Day, 1991. It became a turning point in my life. Although I have been working in the AIDS legal field since 1985 and I know just about everything there is to know about AIDS, my first reaction was, "I'm going to die!" It took me several months to psychologically adjust to the idea of being HIV-positive. I was in a state of shock for a couple of months. I stopped speaking to my parents because they would know something was wrong. I had to apologize to my students at the end of that semester because I simply was not there for them as a professor. Because I have HIV, I may face rejection from employers, friends, neighbors or family; if my doctor denied me treatment, I would not have much left to live for and would give up on trying. However, after a *long* walk along the beach in Acapulco, I soon began to realize not that much had changed in my life. I began to think beyond death to how I was going to *live* with HIV. One of my major concerns became my health status and my medical care. I would need regular medical attention. But a major concern was whether I might face a situation where a health care professional would not treat me because of my HIV status.

As I began accepting myself as HIV-positive, medical care emerged as a pre-eminent concern. My usual doctor and my dentist treat many AIDS patients, so my concern was not about my immediate care. But the future, and the fear of serious illness raised many questions. If I need emergency care, will the paramedics treat me if they are aware of my HIV status? When I am travelling, which is quite often, will I be able to find a doctor, dentist or other health care professional to treat me, if necessary, wherever I go? Should I carry a card in my wallet stating my HIV status? If I decide not to tell a doctor in order to receive treatment, will I be compromising my health because he or she may be missing a vital piece of information which could change my course of treatment? Do I even have to tell them my HIV status?

As an attorney, I have followed proposed legislation which would make it a criminal offense to fail to inform a health care professional of one's HIV status. These laws concern me, not only as

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an advocate for AIDS patients, but also on a personal level. I personally have to weigh whether or not I would be a danger to a health care professional if I did not inform him or her of my status versus my own rights to privacy. Even as a lawyer, I admit the thought did not cross my mind that failing to disclose my HIV status to a medical person might subject me to penalties. I must determine if it is in my best interest to inform the person, as well as what risk I might possibly pose to the person, if I do not disclose my status. If I believe someone is inclined not to treat me and I need the treatment immediately, the thought of criminal penalties for not telling that person will not enter into my decision. I do not feel such punitive sanctions will be effective and, in fact, will be very counter-productive because some persons may not seek medical attention as a result. We do not need to fine persons who are probably already impoverished or slap them in jail where medical attention is, at best, lacking.

The current state of the law is relatively unclear on the legal obligation of an HIV-infected patient to inform a health care professional of his or her status. There has been some litigation where medical professionals have sued hospitals or local authorities when the hospital patients did not disclose their status.¹ Some courts find an obligation to inform while others find no obligation to disclose.² The courts will continue to grapple with this issue, but I believe they will continue to decide these issues on the distinct facts of each case, based on an individual jurisdiction's tort laws. Do I believe I have a legal obligation to inform a health care professional of my HIV status? Under most circumstances, my answer is no. Because all health care professionals are already supposed to use universal precautions, the knowledge of a patient's HIV status should make no difference in deciding whether to treat someone; the distinction is in the substantive treatment given. I feel differently in surgical procedures which involve much more invasive and potentially dangerous procedures such as orthopaedic operations. In these circumstances, I know there is not much which is done differently on an HIV-positive patient than on a non-infected patient, but the potential risk to the operating room personnel could be greater. I would still expect the health care professional to treat me in the same manner as a non-infected person, but I can see a stronger legal case being made for disclosure to the surgical staff. In any event, I believe it is best if medical personnel know of my

1. *E.g.*, *Ordway v. County of Suffolk*, 583 N.Y.S.2d 1014 (N.Y. Sup. Ct. 1992); *Doe v. New York*, 579 N.Y.S.2d 822 (N.Y. Ct. Cl. 1991); *Johnson v. W. Va. Univ. Hosps.*, 413 S.E.2d 889 (W.Va. 1991).

2. *See Ordway v. County of Suffolk*, 583 N.Y.S.2d 1014 (N.Y. Sup. Ct. 1992) (finding, based on privacy rights, that no duty existed for county to inform the doctor of a patient's HIV status).

HIV status for purely medical reasons. Without that knowledge, a medication might be prescribed which could be harmful to my immune system such as immunosuppressive drugs.

Throughout my legal career, I have assisted many clients who have been denied medical services because of their HIV status. Most notable was a client who was walking on a boardwalk on a beach in Delaware. He cut his foot on a nail and his friends rushed him to a hospital. The doctor at the hospital demanded to know whether the client had taken an HIV-antibody test and refused to treat the client until the client replied. The client had not taken a test, so the doctor refused to treat him. When the client asked the doctor why he was refusing treatment, the doctor stated he was afraid of AIDS. The client had to be airlifted by helicopter to Washington, D.C., for treatment. The delay in treatment caused permanent damage to his foot. Later, the press asked the doctor why he wanted test results. The doctor replied he thought the client was gay because of "his demeanor, and one of his friends was wearing a 'Blondes Have More Fun' T-shirt, and was blond."³ Because of the doctor's perception, whether correct or not, the patient was denied immediate necessary medical attention which resulted in permanent damage. The client later sued the doctor and the hospital, and the Office of Civil Rights of the Department of Health and Human Services investigated both providers. The hospital in turn fired the doctor. The harm had already been done resulting in permanent foot damage. The situation sent a loud message to HIV-infected people that they risk their personal health if they disclose their status.

In another instance, a client went to a Veterans Administration hospital for an operation. A resident at the hospital informed him she did not want to treat him because he was HIV-positive, and she sent him home for other reasons. The client chose not to pursue the matter.

Additionally, I have handled several complaints against dentists who refuse to treat HIV-positive patients. The dentists give a variety of excuses to avoid providing treatment. In one instance, a pregnant dentist read that people with HIV could be a threat to pregnant women and their unborn children. Many other dentists refuse treatment or services because they say their other patients will stop coming to them if they know the dentists are treating HIV-infected patients. During my first year teaching at the District of Columbia School of Law, I conducted a training seminar to educate dentists about their legal obligations and responsibilities to HIV-infected patients. The local dental association co-sponsored the

3. Lou Chibbaro, Jr., *Doctor Refuses to Treat Beach Visitor He Thinks Is Gay*, THE WASH. BLADE, July 10, 1987, at 3.

seminar. In attendance was my dentist, who is very familiar with HIV risks in dental practice. Because I am a client/patient in the relationship with my dentist, my perspective about the dentist's obligations to treat patients differed from that of the dentists. It took me a while to figure out why all the dentists present asked certain questions, such as "When can I refer a patient?", or "Do I have to tell my other patients?" My dentist made a remark about being tired of accepting referrals from others who claimed they did not have the "expertise" to treat HIV-positive patients, and then whispered to me, "It's the usual story—they're here to see how they can legally avoid seeing HIV-positive patients." He had been dealing with this for quite some time, both in his practice and with the dental association. Our message to the dentists was that they could not avoid treating these patients, and that they probably are treating HIV-positive patients already.

I relate these "war stories" for a purpose. While a patient's obligation to inform a medical professional of his or her HIV status may be unclear, it is well settled that a medical professional's refusal to treat is both illegal and unethical. I have worked with the public accommodation provisions of both the Federal Rehabilitation Act of 1973⁴ and the D.C. Human Rights Act⁵ to protect my clients from discrimination. More recently, I am using the Americans with Disabilities Act.⁶ When I began my legal career, little did I realize that I would be using these laws to protect myself as well. I know the refusal of a doctor or dentist to treat me will subject that doctor or dentist to liability under any of these laws. I could sue the doctor and the hospital or file an administrative complaint under the D.C. Human Rights Act or sue under the applicable federal act. I could also file an ethical complaint with the doctor's licensing board. The American Medical Association stated outright that it is an ethical violation for a doctor to refuse to treat an HIV-positive patient.⁷ The American Dental Association has similar guidelines.⁸ Most state and local licensing authorities either follow these professional guidelines or have adopted their own. Courts give great deference to the professional associations' guidelines and will find a legal, as well as an ethical violation, for a refusal to treat. Courts often adopt these guidelines as the reasonable standard of care for a doc-

4. 29 U.S.C. §§ 794-797 (1973).

5. D.C. CODE ANN. §§ 1-2501-2557 (1977).

6. 42 U.S.C. §§ 12101-12213 (supp. 1992).

7. See generally AMA Council on Ethical and Judicial Affairs, *Ethical Issues Involved in the Growing AIDS Crisis*, 259 JAMA 1360 (1988).

8. AMERICAN DENTAL ASSOCIATION, PRINCIPLES OF ETHICS § 1 (1994); AMERICAN DENTAL ASSOCIATION, CODE OF PROFESSIONAL CONDUCT 1-A (1994). The American Dental Association says it is unethical to deny treatment based solely on the patient's HIV status. AMERICAN DENTAL ASSOCIATION, CODE OF PROFESSIONAL CONDUCT 1-A, Advisory Opinion 1 (1994).

tor or dentist in that community, and a refusal to treat is often a violation of the reasonable standard of care. Therefore, a medical professional may face a malpractice suit, in addition to a discrimination or civil rights suit, and an ethical investigation.

As I consider whether to tell a doctor or dentist of my HIV status, I know these laws will eventually protect me, even if it takes a lawsuit to do so. But a lawsuit does not help me if I need immediate attention and the health care professional refuses to treat me. My familiarity with a doctor or dentist, my comfort level with them, their attitude, and my impression of their professional judgment all play a role in whether I will disclose my HIV status or not.

In 1983, I was in a motorcycle accident in which I broke both legs. I still suffer problems with my legs, especially my knee. I have made it a point to see the orthopaedic surgeon who performed the original surgery on me at least once a year since my recovery. Last winter, my knee swelled, almost locked up, and hurt a great deal. I went to the doctor, who injected my knee with cortisone. We discussed future options, including surgery, if my knee did not improve. At that point, I began to think about telling him because I didn't know of any interactions any prescribed medications might have, and I wanted him to be fully aware of the situation in case we decided on an operation. But, my right brain said that this is a top doctor in a *very* suburban, upper middle-class practice who probably has not seen an HIV-positive patient and may not react well. My left brain argued that I had to tell him if I were going to have surgery or be on medication. I felt an ethical/quasilegal obligation to inform the doctor, and my left brain won out. I nervously said, "Doctor, I need to tell you something . . . (dramatic pause) . . . I'm HIV-positive." I was greatly relieved by his body language because he didn't even flinch. He responded warmly to the effect that it would not affect my course of treatment, even including surgery. I made the decision to place my trust in his professional judgment, as I had so many times before. I was rewarded with an appropriate professional, *and human*, response. This response encouraged me to continue to inform any health care professional I may have to see in the future.

Recently, I won a battle against a sinus infection. It lasted several months and I had been on ten different antibiotics, all without result. My regular doctor treated me with antibiotics, which had no effect. He sent me to have X-rays, then referred me to a specialist after seeing the results. Because this was a specialist to whom my doctor frequently refers patients, I was not too concerned about informing him of my HIV status. I also knew that chronic sinusitis is often a symptom of HIV-infection, so I felt especially compelled to inform the specialist. The specialist tried more antibiotics. When this did not help, the specialist ordered a CAT scan. The scan re-

vealed a fairly massive and resistant infection. The specialist then referred me to a second specialist. This second specialist was concerned with my CAT scan, and discussed possible surgical or semisurgical procedures with me. He may have already known my HIV status because he spoke to the first specialist about my case. I did inform the doctor of my HIV status during our first appointment. This specialist tried four different antibiotics and waited to see whether they worked. I thought I was going to have a "sweep" of my sinuses to clear the problem, but instead I got the new antibiotics. I was waiting to finish the present course of antibiotics, but after this course of drugs, I did not want to subject my body to further experiments. I understood he wanted to try the newer, stronger drugs, but I could not help harboring a lingering suspicion that he was avoiding any sort of invasive procedure because of my HIV status. I was unwilling to state this suspicion openly, but the suspicion grew every time he insisted I stay on the drugs just a little longer. Given these facts, I really felt that he was discriminating against me because I was being treated differently from someone who did not have my disabling condition. Fortunately, my suspicions were only suspicions and the doctor, after seeing no improvement, performed the necessary procedures.

In the instances I cited above, I raise several points: (1) my comfort level and familiarity with the doctor; (2) how I correctly determine if a doctor is hesitant to treat; and (3) what recourse I have if the doctor is hesitant, except in the case of outright denial. So many of these issues can be subjective. I am receiving the same treatment from my orthopaedic surgeon as would any other patient who is not HIV-infected. I have known the surgeon for over ten years now. My familiarity with the doctor and his familiarity with me may play a factor in this, but as a surgeon, he is still at higher risk because of my HIV status if we decide to proceed with an operation. Yet with my ear, nose and throat doctor, I suspected I was being treated differently because of my HIV status. At the moment I have no way to confirm my suspicions, which may simply be just that—suspicions. I understand all invasive procedures may contain some risk for the doctor, but normal, reasonable precautions and sterilization procedures are adequate to protect him in a sinus sweep. I did not want my HIV status to keep me from suffering with this infection any longer than necessary.

I know fully what my rights are under the laws cited above. Yet I also know I have no proof of my suspicions and a discrimination complaint or lawsuit would be extremely difficult to prove without strong expert testimony. I also find myself afraid to confront the doctor to allay my fears. I believe this is a common feeling among patients with any doctor for any condition. In the case of HIV, it is more vital that the doctor-patient relationship be as open

and honest as possible. Perhaps if I did confront my doctor, it would spur him on to more fully explain why he was keeping me on the drugs. I believed asking would almost certainly offend him. I also felt my treatment could suffer if he continued to see me at all. But on the other hand, I deserve the same treatment as non-infected patients. If my suspicions are valid, I was not getting the treatment I needed and it would have been best to find someone who would perform the necessary procedures. I also know I could pursue a complaint or lawsuit, as difficult as that might be.

Knowing the law does not help me decide what I should do in this case. If I cannot decide with all my legal experience and knowledge about HIV, I can only imagine what my clients do when confronted with a similar situation. I also wonder if health care professionals understand or are even aware of patient concerns such as these. Most patients place doctors on pedestals and do not question the treatment method prescribed. However, many persons with HIV do question treatment decisions and doctors have had to learn to work with aggressive patients. Having gone through this experience, I advise a patient and doctor to discuss these issues at the beginning of the professional relationship so all parties are comfortable with the medical services being provided. Clearly, this is more difficult if one has not disclosed his or her HIV status. I encourage my clients to disclose and I also reassure them the law will protect them because it is medically important for the doctor to know this information.

Simply because I know the law does not mean that I will always be able to use it to my advantage. I have wrestled with the question of whether to carry a medical card in my wallet which states my HIV status in case of an emergency. Should I be in a car accident and lose consciousness, I want the best emergency treatment I can receive. But if an emergency medical technician (EMT) discovers my HIV status through such a card in my wallet, will the EMT perform whatever procedures might be necessary to save my life? What if I need mouth-to-mouth resuscitation? While most EMTs carry proper equipment to protect them, what if an off-duty EMT comes by first, as happened in my motorcycle accident, and does not have the proper equipment? Will the EMT still give me that potentially life-saving procedure? Knowing the law protects me would do me absolutely no good in that situation. I would have to trust the professional training, knowledge, and judgment of the EMT, as well as the EMT's ability to overcome his or her own fears and prejudices about HIV.

I never lost consciousness after my motorcycle accident, but I was certainly in a state of shock. If the same situation happened now, I can rationally think I would tell the EMT on the scene of my HIV status, particularly if there were a lot of blood. But from expe-

rience, I also know I would not be thinking rationally because of the shock. Would the question of my HIV status even come to my mind through the pain and commotion going on around me? I honestly cannot answer that question. I only vaguely remember what happened to me immediately after the accident except for fleeting memories of pain, many people around me, arriving at the hospital in the ambulance (but not the ambulance ride itself), and several questions from the doctors in the emergency room. I could not tell you now what I was asked nor what my responses were. That accident occurred in 1983; one of the questions in 1993 could well be, "Are you HIV-positive?" This question did not even exist in 1983. How would I answer in shock and in pain from the impact of the collision? My tendency is to believe I would say yes, simply because it's the truth. Under those circumstances, I would not be in a frame of mind to think through the consequences of answering that question honestly. I hardly think criminal penalties would enter my thoughts if such a law sought to compel disclosure. Fear of denial of treatment would come to my mind if I disclosed my status, especially when there was a lot of blood because it is a valid, presently existing fear. I cannot answer as to whether I would tell the doctor or not. But my left brain is telling me, "Sure, I would tell because I can handle this," while my right brain screams loudly for painkillers and doesn't want to say anything until it gets those painkillers.

Another factor to consider is location. If I am in a large city, I feel more confident that an EMT would have either already dealt with a person with HIV or at least have had some training on the subject given the higher incidence of HIV in larger cities. However, if I am driving cross-country and I am in a rural area, I would be much more hesitant to disclose my HIV status. I would not know if the EMT has had HIV training, even if I believe it should be mandatory for all medical personnel. I do not know that particular EMT's concept of a person with HIV and the EMT's prejudices towards those with HIV. I feel I would hesitate to tell the EMT because of these fears. Yet, if I saw the person somehow immersed in my blood without using universal precautions as part of the medical procedures, I know I would feel compelled to stop the process, assuming I were conscious and able to do so. I would again face my internal struggle—if I tell my HIV status, will they continue to treat me? If I don't, will they wonder why I stopped them and be hesitant to treat me anyway or will they continue because I'm crazed with pain? The entire dilemma repeats itself. If and when I disclosed, I would be concerned the EMT's attitude towards me would change.

If I then needed hospitalization, knowing that rural or suburban hospitals have turned away HIV-positive persons, I fear I would not get the treatment I need at the time. I could cite the law

against discrimination to the people around me, but I know from experience this often has little effect when dealing with HIV. If I were denied treatment, once I had received proper medical treatment later, I know I would pursue whatever legal action was necessary to punish those who wrongly denied me treatment. I know the law, and I am willing to take such action. I also know from professional experience that many HIV-infected persons are turned away from treatment, usually for minor ailments where no emergency exists. They almost never take any legal action. Is it worth it for them to file a complaint? In my mind, it is a valuable opportunity because I want to make examples of the medical personnel who should know better. But as a lawyer, and a plaintiff in a discrimination suit against an insurance company several years ago, I also learned how much time and energy it takes to pursue legal action. To many HIV-positive persons, it is just as easy to avoid the hassles and find someone who will treat them. Particularly for someone who is very ill or becoming ill, the thought of a lawsuit only adds to the draining physical and mental process of AIDS. As a plaintiff's attorney, I would have to discuss these issues with the client, including whether the client would live long enough to pursue a case and whether the client is able to withstand grueling depositions and other legal procedures.

I intend to inform any health care professional who treats me of my HIV status. I fully understand this may cause me to be denied treatment at some point. But I will still do this for several reasons. First, this puts the medical professional on notice that I am considered a disabled person under the laws and cannot be denied the treatment without recourse against the medical professional. I have the legal right to receive the same treatment as a non-infected person. Second, I believe that to receive the best medical treatment possible, a doctor must have all the relevant medical facts so he can adjust the course of treatment, including medication, to take the HIV into account. This may mean more intensive treatment than a non-infected person may receive, but it is in my best interest to reveal my condition. Third, I personally feel an ethical obligation to inform health care professionals of my status even though I know all medical personnel are supposed to use universal precautions. If I inform the person, that person will certainly use universal precautions if he or she were not doing so already. Finally, I feel that disclosing my HIV status will make the professional relationship between doctor and patient better because there is more trust on each side, the patient will be more confident in asking questions about the treatment and the doctor will more fully disclose what treatments he is giving and why.

As more and more cases of HIV arise, patients with HIV will become more common in almost every doctor's practice. These doc-

tors and other medical professionals have a legal and ethical obligation to treat a patient with HIV. More education among health care professionals as well as persons with HIV is necessary to help battle the discrimination which occurs more often than is realized. My hope is that this topic will become moot because all persons are being treated in a caring, professional manner to help all of us with HIV to live better lives.